

Cancer Registries:

The Foundation for Cancer Prevention and Control



"Having complete, timely, high-quality cancer data from throughout the United States is essential to identifying, understanding, and controlling our nation's cancer burden."

James S. Marks, MD, MPH
Director, National Center for
Chronic Disease Prevention
and Health Promotion

Cancer Registries: Collecting Data for Cancer Prevention and Control

Cancer: Second Leading Cause of Death

In 2002, half a million Americans will die of cancer—that is more than 1,500 people a day. One of every four deaths in America is from cancer.

The American Cancer Society (ACS) estimates that 8.9 million Americans have a history of cancer. In 2002, about 1.3 million new cases of cancer will be diagnosed. This estimate does not include the number of cases of in-situ (preinvasive) cancer or

the approximately 1 million cases of nonmelanoma skin cancer that will be diagnosed this year.

Effective prevention measures exist to substantially reduce new cases of cancer and prevent many cancer deaths. Reducing the nation's cancer burden requires reducing the prevalence of behavioral and environmental factors that increase people's cancer risk, as well as ensuring that screening services and high-quality treatments are available and accessible to everyone in America.

Cancer Registries: Essential to Reducing the Burden

Cancer registries collect data about the occurrence of cancer (incidence), the types of cancer that occur, the

State cancer registries are designed to

- Monitor cancer trends over time.
- Determine cancer patterns in various populations.
- Guide planning and evaluation of cancer control programs (e.g., determine whether prevention, screening, and treatment efforts are making a difference).
- Help set priorities for allocating health resources.
- Advance clinical, epidemiologic, and health services research.
- Provide information for a national database of cancer incidence.

cancer's location in the body, the extent of disease at the time of diagnosis (stage), and the kinds of treatment patients receive. Cancer data are reported to a central statewide registry from various medical facilities including hospitals, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, and pathology laboratories.

Data collected by state cancer registries enable public health professionals to better understand and address the cancer burden. Registry data are critical for directing programs focused on preventing risk behaviors for cancer (e.g., tobacco use, sun exposure) and reducing environmental risk factors (e.g., radiation, chemical exposures). Such information is also essential for identifying when and where cancer screening efforts should be enhanced and for monitoring the treatment provided to those diagnosed with cancer.



DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention

CDC's National Program of Cancer Registries

Providing National Leadership

Since 1994, the Centers for Disease Control and Prevention (CDC) has administered the National Program of Cancer Registries (NPCR). The NPCR currently helps states and territories to

- Improve cancer registries.
- Meet standards for data completeness, timeliness, and quality.
- Develop model laws and regulations to strengthen registry operations.
- Train registry personnel.
- Establish a computerized reporting and data processing system for registries.
- Use cancer data to support cancer prevention and control programs.

Before the NPCR was established, 10 states had no registry, and most states with registries lacked the resources and legislative support to collect needed data. With fiscal year 2002 appropriations of approximately \$40 million, CDC now supports central registries and promotes the use of registry data in 45 states, the District of Columbia, and the territories of Puerto Rico, the Republic of Palau, and the Virgin Islands. CDC is also

developing research projects such as studies to examine patterns of cancer care in specific populations. CDC's goal is for all states to establish registries that provide high-quality data on cancer and cancer care.

CDC's NPCR complements the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) registry program. Together, the NPCR and SEER programs collect data for the entire U.S. population. The SEER program gathers in-depth data on cancer cases diagnosed in Connecticut, Hawaii, Iowa, New Mexico, and Utah, as well as in six metropolitan areas and several rural/special populations areas. The six metropolitan SEER registries and some of the rural/special population registries submit their data to the NPCR's state central registries.

In 2001, SEER began providing additional support to four NPCR-supported state registries—California, Kentucky, Louisiana, and New Jersey. The goal of this expansion is to increase coverage of key populations, such as more diverse Native American populations, rural African Americans, rural low-income whites, and more Hispanic groups.

Expanding Efforts To Improve and Use Cancer Data

Assisting States

CDC provides leadership and support to

- Provide on-site technical assistance to registry personnel to help ensure data completeness, timeliness, and quality. For example, CDC has developed software to facilitate data transmissions and improve the quality of data that hospitals transmit electronically to cancer registries.
- Coordinate and convene meetings of registry personnel for information-sharing, problem-solving, and training.
- Help states and national organizations use cancer data to describe state and national disease burdens, evaluate cancer control activities, and identify populations at high risk for certain cancers.
- Collaborate with federal, state, and private organizations to design and conduct research using data collected through state registries.

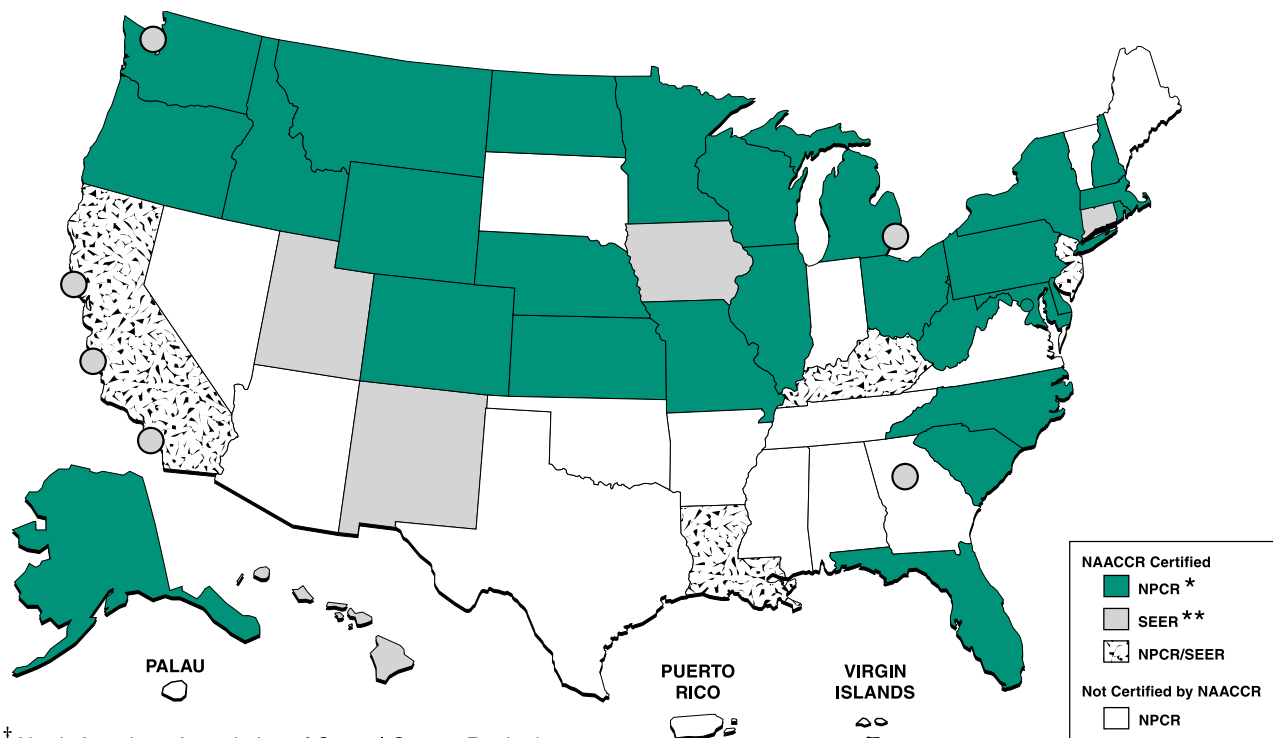
Ensuring the Quality of Registry Data: CDC Standards and NAACCR Certification

CDC has established national standards to ensure the completeness, timeliness, and quality of cancer registry data. In addition, CDC recommends that central cancer registries incorporate standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR). In 1997, NAACCR instituted a program that annually reviews member registries for their ability to produce complete, accurate, and timely data. Registries that achieve the highest standards receive NAACCR certification. During the first 5 years of the certification program, the number of CDC-supported statewide registries that met these high standards increased from 9 to 32.

Implementing the NPCR—Cancer Surveillance System

CDC's NPCR presents a unique opportunity to strengthen cancer reporting in the United States. The NPCR collects information on cancer cases from registries that cover

NAACCR[†] – Certified U.S. Cancer Registries: 2002



[†] North American Association of Central Cancer Registries.

* National Program of Cancer Registries.

** Surveillance, Epidemiology, and End Results Program.

Note: Certification based on data for cancers diagnosed in 1999

96% of the nation's population. In 2001, for the first time, CDC received state data for entry into the NPCR–Cancer Surveillance System (CSS). Registries submit data to the CSS once a year. This system is providing valuable feedback to help state registries improve the quality and usefulness of their data and link with other existing databases. The availability of regional and national data also will facilitate studies in areas such as rare cancers, cancer among children, cancer among racial and ethnic minority populations, and occupation-related cancer.

Using Data To Prevent and Control Cancer

The NPCR enables reporting of cancer data by age, sex, race/ethnicity, and area—within a state, between states, and between regions. Special emphasis is placed on obtaining cancer information on residents who travel to other states for diagnosis or treatment. Comprehensive, timely, and accurate data about cancer incidence, stage at diagnosis, first course of treatment, and deaths are used to evaluate the effects of cancer prevention and control efforts and progress in meeting health objectives. States use registry data in diverse ways, as the following examples illustrate:

Colorado Central Cancer Registry (CCCR) data are being used to conduct an epidemiological evaluation of cancer and occupational exposures at the Rocky Flats Environmental Technology Site. A roster of more than 20,000 current and former Rocky Flats workers is being matched with CCCR files to examine cancer risks from radiation doses and chemical exposures.

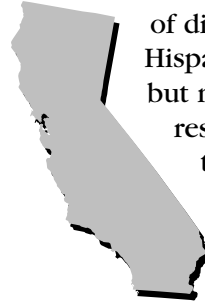
The **Missouri Cancer Registry/Office of Surveillance, Research, and Evaluation**, in collaboration with the state's Center for Health Information Management and Evaluation, has developed a unique cancer information resource for citizens, health professionals, researchers, and policymakers. The Missouri Information for Community Assessment (MICA) is a breakthrough effort in providing an easy-to-use, interactive Internet site where users can access both cancer statistics and information about health risk factors.





In a *New Jersey State Cancer Registry* study using geographic information systems, two areas in the northeastern part of the state were identified as having unusually high proportions of late-stage breast cancer. More than 90% of the women diagnosed with breast cancer lived within 2 miles of a mammography screening center. Demographic information showed that the populations of these communities were more likely to be black, Hispanic, or foreign-born, and to speak a language other than English at home. To increase screenings in these areas, New Jersey has produced culturally sensitive information about the availability of screening in a variety of languages, such as Spanish, Polish, and Arabic. The state also has provided training in cultural sensitivity and diversity to staff working at the screening centers.

From 1988 through 1999, the *California Cancer Registry* studied the incidence of cancer among members of the United Farmworkers of America (UFW), a largely Hispanic farmworker labor union. Results showed that the risk of leukemia, stomach, cervical, and uterine cancers was elevated in California farmworkers.



UFW members also experienced later stage of disease at diagnosis than other California Hispanics for most major cancer sites, but not for breast cancer. Additional research into the potential causes of this increased risk for certain cancers is planned, including a study of farmworkers' exposure to pesticides.

CDC's Collaborations in Cancer Monitoring

In addition to providing financial and technical assistance to state cancer registries, CDC also works with various private sector organizations, the NCI, the Department of Veterans Affairs, the Indian Health Service, the Department of Defense, and other federal agencies to support cancer surveillance efforts. Examples of collaborative activities include the following:

New Federal Cancer Statistics Publication

This Fall, CDC's NPCR and NCI's SEER program will jointly publish federal cancer statistics for all states that have high-quality data. This publication will provide cancer statistics for cases diagnosed in 1999 and will cover about 78% of cancers diagnosed in the United States that year. State-specific cancer statistics will be included from about 40 states.

National Coordinating Council for Cancer Surveillance

CDC participates in the National Coordinating Council for Cancer Surveillance, a consortium that also includes the ACS, the NCI, the American College of Surgeons, NAACCR, and the National Cancer Registrars Association. The Council provides a forum for these organizations to collaborate on cancer monitoring and registry operations.

Report to the Nation on the Status of Cancer

Another collaborative project is the *Annual Report to the Nation on the Status of Cancer, 1973-1999*, produced jointly this year by the ACS, NCI, CDC, NAACCR, and the National Institute on Aging. This series of cancer reports has been published annually since 1998. The 2002 report includes a special section on the implications of age and aging on the nation's cancer burden.

CONCORD Study: An International Collaboration

The CONCORD study, a large trans-Atlantic project, will measure and explain differences in cancer survival between Europe, Canada, and the United States. The study focuses on breast, prostate, and colorectal cancers. Population-based cancer registries in 17 NPCR-supported states, 6 Canadian provinces, and 16 European countries are participating in various phases of this study, designed to determine the extent to which international differences in cancer survival can be attributed to differences in tumor biology, disease definition, stage at diagnosis, treatment, and health care systems, or to other factors.

For more information or additional copies of this document, please contact:

Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

Mail Stop K-64, 4770 Buford Highway, NE, Atlanta, GA 30341-3717
(770) 488-4751 • Voice Information System 1 (888) 842-6355 • Fax (770) 488-4760
cancerinfo@cdc.gov • <http://www.cdc.gov/cancer>